

# Current Issues in HIV Counseling and Testing in South and Southeast Asia

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January 2000

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Population Council is an international, nonprofit, nongovernmental institution that seeks to improve the wellbeing and reproductive health of current and future generations around the world and to help achieve a humane, equitable, and sustainable balance between people and resources. The Council conducts biomedical, social science, and public health research and helps build research capacities in developing countries. Established in 1952, the Council is governed by an international board of trustees. Its New York headquarters supports a global network of regional and country offices.

Family Health International (FHI) is a nonprofit, nongovernmental organization founded in 1971 and dedicated to improving the health of women, men and children around the world, with special emphasis on reproductive health and the prevention of sexually transmitted infections (STIs), including HIV. Through 14 years of institutional development, technology transfer, information dissemination and training, FHI has implemented more than 1,200 HIV/AIDS/STI projects in 60 countries. FHI has strengthened the prevention and care programs and services offered by more than 500 nongovernmental organizations, community groups and private businesses, making it the world's leading private organization working to prevent further spread of HIV and enhance the care and support for those infected with and affected by HIV/AIDS.

This publication was made possible through support provided by the United States Agency for International Development, under the terms of Cooperative Agreements No. HRN-A-00-97-00017-00 (IMPACT Project/Family Health International) and HRN-A-00-97-00012-00 (Horizons Project/Population Council) through USAIDS's office of Health and Nutrition, Global Bureau). The views expressed in this report do not necessarily reflect the policies of U.S. Agency for International Development or Family Health International.

# Acknowledgements

This report is an outcome of a workshop held in February 1999 in Mumbai, India. We are grateful to the following participants for their valuable contributions towards the preparation of this report:

Christopher Castle, Margaret Dadian, Mandeep Dhaliwal, Laelia Gilborn, Philip Guest, Claudes Kamenga, Vaishali Sharma Mahendra, Mary O'Grady, Eric van Praag and V.L. Thomas.

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## Abbreviations

AIDS.....	Acquired Immunodeficiency Syndrome
AIDSCAP.....	AIDS Control and Prevention Project
AZT.....	Zidovudine
FHI.....	Family Health International
HIV.....	Human Immunodeficiency Virus
MPACT.....	Implementing AIDS Prevention and Care
MCH.....	Maternal and Child Health
MTCT.....	Mother-to-Child Transmission
NGOs.....	Non-governmental Organizations
PLWHA.....	Persons Living with HIV or AIDS
UNAIDS.....	Joint United Nations Programme on HIV/AIDS
USAID.....	United States Agency for International Development
VCT.....	Voluntary Counseling and Testing
WHO.....	World Health Organization

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# Abstract

In February 1999 the Population Council and Family Health International brought together scientists, policy-makers, health service providers, activists and members of the community to discuss some critical issues concerning HIV counseling and testing in the South and Southeast Asia region. The following summarizes important points that emerged over the course of the workshop.

In many countries of the region, HIV testing has been viewed as an approach to track down and isolate persons living with HIV or AIDS (PLWHA). Insufficient attention has been paid to maintaining informed consent and confidentiality procedures, and widespread stigmatization and discrimination against PLWHA persist in much of the region. This contributes to public avoidance of HIV counseling and testing.

More humane and person-centered programs are needed, that focus not so much on HIV testing but on counseling and other services that address the diverse needs and rights of individuals at risk of acquiring HIV infection or currently living with HIV/AIDS. This implies that HIV testing services should be integrated into more comprehensive programs of HIV prevention and care. This is critical for PLWHA for whom HIV counseling and testing should serve as an entry point to a continuum of care program.

- Voluntary HIV counseling and testing plays a pivotal role in interventions to prevent mother-to-child transmission of HIV. Participants discussed the important initiatives taken in this regard in Thailand. They urged that more attention be paid to meeting the broader human and societal needs of the mothers themselves, especially with regard to consent, confidentiality, and ongoing personal care and support.
- In planning HIV counseling and testing programs, the challenge is to expand access to services, while ensuring that they meet basic standards with respect to the practice of informed consent, the quality of the counseling, the validity of the HIV test, and confidentiality. The participants reviewed various service delivery models and discussed the implications of new technologies.
- There is a need to develop policies and laws regarding HIV testing through processes that are informed by public health expertise and human rights concerns. These activities should hasten the "normalization" of HIV/AIDS and thus support other control efforts.
- Questions to guide operations research in support of the development and expansion of voluntary counseling and testing programs in the region were identified and are listed at the end of the report.

# Introduction

As the HIV/AIDS pandemic spreads throughout South and Southeast Asia, there has been much debate in recent years about how best to incorporate HIV counseling and testing services into HIV/AIDS prevention, care, and support programs in the region. A wide variety of views exist about which approaches are most feasible, acceptable, and cost-effective. New public health imperatives, such as the prevention of mother-to-child transmission (MTCT) of HIV, and difficult human rights issues also challenge counseling and testing service providers. Throughout the region, some countries have substantial programmatic and research experience in HIV counseling and testing, while others are still developing national policies and designing pilot interventions.

In recognition of the potential for regional exchange of views and experiences on this important issue, the Population Council's Horizons Project and Family Health International's Implementing AIDS Prevention and Care (FHI/IMPACT) Project organized a three-day workshop from February 1-3, 1999, in Mumbai, India, with the following objectives:

- To review relevant research and program experiences related to HIV counseling and testing in South and Southeast Asia.
- To debate critical issues in the design and

implementation of HIV counseling and testing policies and programs, with a particular focus on the Indian context.

- To identify priorities for operations research.

The workshop brought together a diverse group of scientists, policy-makers, health service providers, activists, and community members. Participants came from Cambodia, India, Indonesia, Myanmar, Nepal, Thailand, and Vietnam; representatives of international organizations from other countries also attended. (The list of participants and the agenda are provided at the end of the report.)

This report presents the salient points of the discussion under the following five themes:

- Voluntary counseling and testing as an entry point for HIV prevention and care.
- The role of voluntary counseling and testing in the prevention of MTCT.
- Service delivery models.
- Implications of new technologies.
- Ethical and legal issues.

At the end of the report are questions identified by workshop participants for further operations research.

# Voluntary counseling and testing as an entry point for HIV prevention and care

## The need for a conceptual shift

An important consensus emerged during the workshop on the need to shift focus from HIV testing services toward counseling and other aspects of testing services to better address the diverse needs and rights of both HIV-negative and HIV-positive clients.

Historically, HIV testing has been promoted under the assumption that it facilitates HIV/AIDS prevention and care services. Over the years, HIV testing has been combined with counseling and has developed as an important entry point for a variety of program activities, including behavior change initiatives, interventions to prevent MTCT, and early treatment of opportunistic infections and HIV-related disease - all important program goals. However, the implementation of HIV testing programs also raises many challenges, including the need to respect individual choices and rights and to ensure access to care and support services for those who are HIV-positive.

The participants discussed a number of problems in the current practice of HIV testing services. In many of the countries represented, HIV testing is used to track and isolate persons living with HIV or AIDS (PLWHA). Mandatory HIV testing is common in both private and public hospitals in urban areas throughout the region, especially in conjunction with surgery and obstetric care. Even where informed consent, counseling, and confidentiality procedures exist, many health workers are unfamiliar with them and may omit them altogether. Consequently, testing is frequently

conducted without the client's knowledge or consent, with the results disclosed to other health workers and family members. Under such circumstances, those who test positive often experience psychological distress and face many forms of discrimination. They may be denied treatment, lose their employment, or experience rejection by their families or communities.

There are fears that some of these problems will be exacerbated in the future as the prevalence of HIV infection rises in many countries and requests for HIV testing increase in the context of clinical care, employment, and social institutions such as arranged marriages. Unless the rights and needs of PLWHA are protected and the necessary regulatory and quality assurance procedures are put into place, abuses will continue and many individuals will avoid HIV testing, for fear of the negative consequences that would arise from a positive result. This represents a serious barrier to encouraging voluntary HIV testing in support of behavior change activities and perinatal interventions to reduce transmission of the virus, or as an entry point for care and support to PLWHA.

Participants concluded that HIV testing services should be designed to address the multiple needs and rights of individuals at risk or already infected and should be situated within a more diverse set of programmatic activities. A more humane and person-centered approach to HIV testing could be achieved by moving from "voluntary counseling and TESTING" ("vct") to VOLUNTARY COUNSELING and testing



"Ct") where the primary emphasis would be to reach individuals with effective counseling, condom supplies, and peer and community support. Rather than focus on testing, such an approach would emphasize efforts to reduce stigma and discrimination, seek to "normalize" community perceptions of HIV infection and AIDS, and make counseling services available to all who seek them, regardless of their willingness to be tested.

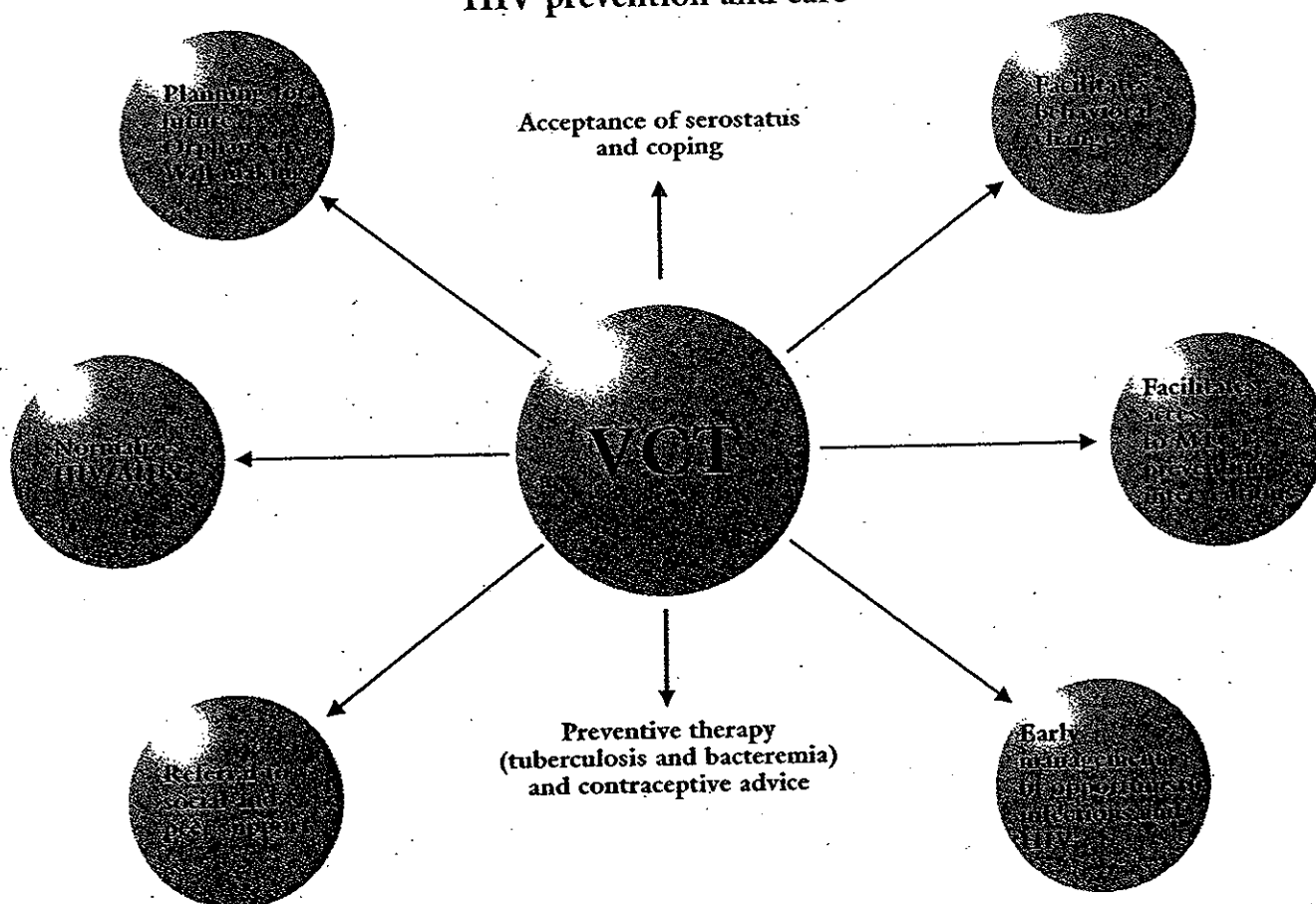
A conceptual framework from the World Health Organization (WHO) was presented showing how such voluntary counseling and testing services can facilitate a wide range of critical interventions for HIV prevention and care (Figure one).

## The role of voluntary counseling and testing in prevention programs

The integration of HIV testing services into more comprehensive programs of HIV prevention and care helps to avoid narrowing the policy choices for supporting voluntary counseling and testing programs.

This issue emerged during a discussion on the potential contribution of voluntary counseling and testing to HIV prevention programs, following a presentation of the results of a collaborative study conducted by FHI's AIDS Control and Prevention Project (AIDSCAP), WHO, and UNAIDS. This multi-

Figure one: Voluntary counseling and testing as an entry point for HIV prevention and care



Source: WHO/Geneva (Initiative on HIV/AIDS/STI)

e, randomized controlled trial, conducted in Tanzania, Kenya, and Trinidad, measured the impact of voluntary HIV counseling and testing on safer sex behaviors. It showed that voluntary HIV counseling and testing among persons seeking such services was more effective in encouraging risk reduction than was the provision of health information alone. In particular, participants who received HIV counseling and testing reported greater decreases in unprotected intercourse with non-primary partners and commercial sexual partners over the six-month follow-up period than those who received only health education.

A cost-effectiveness analysis showed that recurrent costs, such as salaries, represented the largest share of the program costs. While the overall conclusion of the study is that voluntary counseling and testing is a cost-effective intervention for HIV prevention, there was marked variability in cost-effectiveness measures between types of clients, with the intervention found to be most cost-effective among individuals who tested HIV-positive. This raises questions about the potential cost-effectiveness of counseling and testing programs for HIV prevention in lower prevalence settings, as may be found in many parts of South and Southeast Asia. In these areas, the emphasis should probably be on making voluntary counseling and testing accessible to people at higher risk. Even so, given the shortage of health resources in most developing countries, the provision of voluntary counseling and testing might not be as cost-effective as other HIV prevention strategies, such as condom social marketing, improvement in sexually transmitted disease diagnosis and treatment services, and other targeted interventions.

In settings where HIV counseling and testing is not a cost-effective prevention strategy, integrating HIV testing into counseling and other services would likely increase its availability. It would also avoid the potentially wasteful use of resources for vertical HIV such

testing programs that lack links to other support services and are thus of marginal cost-effectiveness and questionable sustainability. While deciding to focus on the most cost-effective interventions is the most rational strategy for guiding resource allocation in primary prevention, the reality is that there are many other important interventions linked to knowledge of HIV serostatus, such as treatment of HIV-related disease. This is particularly true as a community's need for care services increases.

## The role of voluntary counseling and testing as an entry point into care and support programs

Counseling and testing programs also have an important role to play in helping PLWHA access relevant services. The shift of focus from HIV testing to other services is particularly important when one considers HIV testing as an entry point into care and support programs.

A model of the HIV/AIDS continuum of care from WHO was presented to show how voluntary HIV counseling and testing can help PLWHA access a wide range of clinical and support services (Figure two). This model recognizes that PLWHA have many needs that are poorly met by services designed solely to determine serostatus. These needs can only be met by a diverse group of well-trained service providers with skills in pre- and post-HIV test counseling and other skills to support HIV-positive clients in behavior change, partner notification, planning for the future, and coping with the demands of eventual illness. This requires the development of a tight network of clinical and community-based resources to provide medical care and social support, including specific services such as legal assistance and preparation for orphan care. These services are essential for reducing the risk of negative

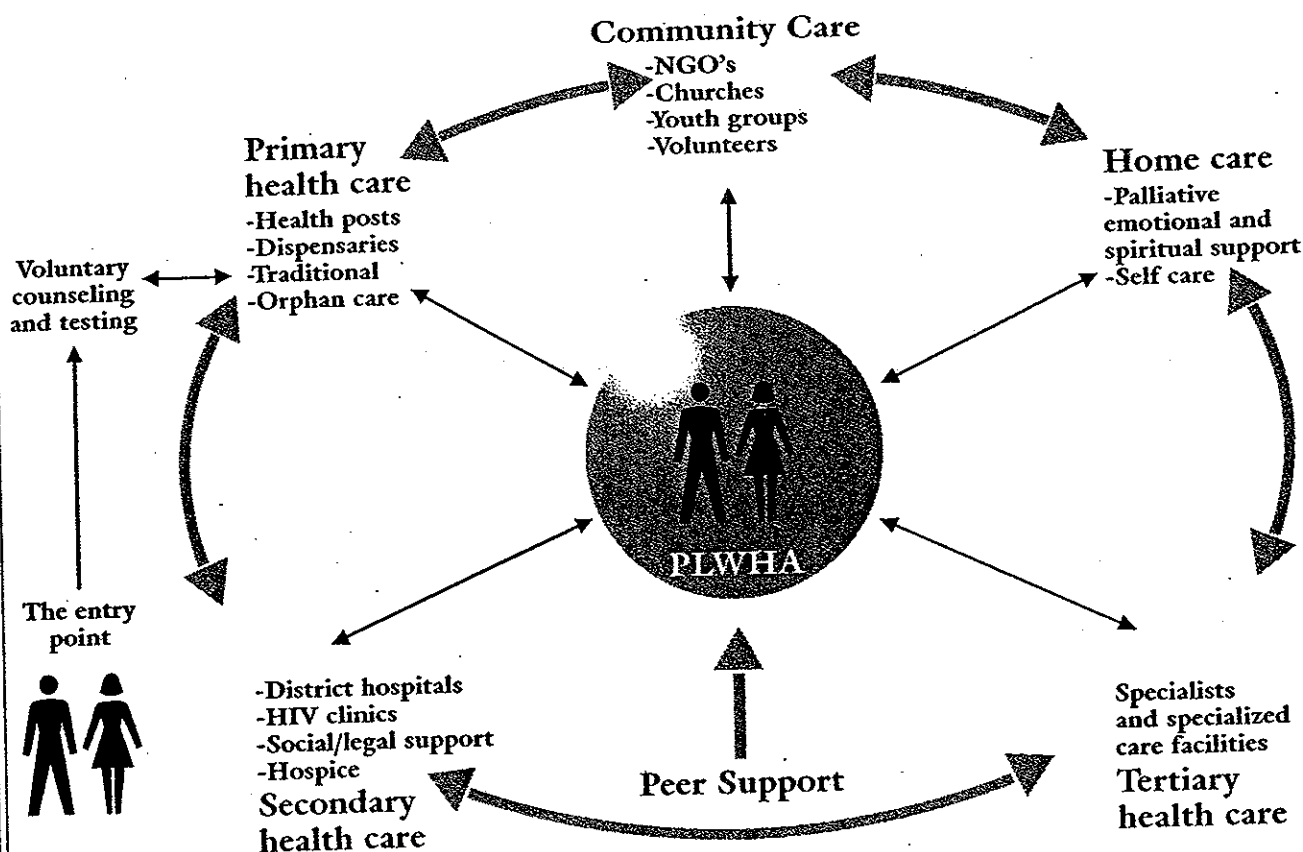
ffects such as demoralization, stress, increased vulnerability to stigmatization and discrimination, and ruptured family relationships. Because they contribute to the social normalization of HIV/AIDS, they benefit not only PLWHA but society as a whole.

PLWHA and their families require carefully planned long-term care and support services. Unfortunately, many existing programs initially included only HIV testing and pre- and post-test counseling services, with follow-up services for PLWHA such as continued counseling, support groups, and clinical care added as an afterthought. In many settings, these services never catch up with rapidly expanding needs.

Many workshop participants felt that a minimum level of services should be in place before HIV testing is widely promoted. It was agreed that any HIV counseling and testing service should at least provide access to continued post-test counseling and referral to long-term care and support.

A number of non-governmental organizations (NGOs) represented at the workshop have taken the lead in developing anonymous HIV counseling and testing centers that protect the privacy and confidentiality of clients. These NGOs provide HIV counseling and other services at sites where individuals can voluntarily come to learn and accept their serostatus. Other NGOs choose

Figure two: The HIV/AIDS Continuum of Care



to conduct HIV testing themselves, due to concerns about the medicalization and attendant abuses of HIV testing. However, they usually provide high-quality counseling and a variety of psychosocial support services to PLWHA and their families.

Many NGOs involved in HIV counseling and testing also advocate for access to care for PLWHA. The experience of workshop participants indicates that comprehensive, high-quality care and support services are feasible even in low-resource settings. In some instances, NGOs have introduced these services into programs for such marginalized groups as alcoholics and drug users. This has come about as program participants move away from HIV-related disease and turn to other health services that prove unable to meet their needs. Community-based and shelter facilities have thus been established to provide palliative care and psychosocial support if these

are not otherwise available to persons with serious or terminal illness. In other cases, NGOs involved in HIV counseling have developed linkages with other NGOs and organizations that offer required services, including specialist medical services, legal assistance, and support groups.

One important feature of many of the programs reviewed was the active participation of PLWHA in the design and delivery of services. Participants expressed strong support for the greater involvement of PLWHA in care and support programs, as both a means of improving the quality and relevance of the services provided and of curbing stigmatization and discrimination. This must be done with caution and sensitivity in order to avoid possible negative consequences for persons involved in activities that increase their visibility as PLWHA.

# The role of voluntary counseling and testing in the prevention of MTCT

A specific example of the need for the conceptual shift from "vcT to VCt" arose in discussions about the challenges of introducing HIV testing into antenatal care services. In this context, testing is advocated primarily for the purpose of identifying pregnant women living with HIV as an entry point for interventions to reduce MTCT. In order to benefit from these interventions, women must know and accept their HIV status. Currently, even in areas of high HIV seroprevalence, most women receiving antenatal care do not know their serostatus and do not have access to voluntary counseling and testing. Where HIV testing is available, maternal counseling (and sometimes consent) has not always been given sufficient attention and is narrowly focused on potential benefits to the newborn of available interventions. The needs of the mother herself are often neglected, especially with regard to confidentiality, protection from discrimination and stigmatization, and ongoing personal care and support.

These issues were discussed with reference to the results of the Thai vertical transmission study that demonstrated the efficacy of a short course of zidovudine (AZT) in decreasing MTCT. The course consisted of 300 mg of zidovudine given to HIV-affected women orally twice a day from 36 weeks' gestation until onset of labor, and every three hours from the onset of labor until delivery. All women were provided with breast milk substitutes and counseled not to breastfeed, in line with national guidelines for HIV-affected women in Thailand. This study reduced MTCT by 50 percent (from 18.9 percent to 9.4 percent),

demonstrating that short courses of antiretroviral therapy can have a significant impact on transmission rates, at least among non-breastfeeding women.

The Thai authorities subsequently addressed the challenge of translating these research findings into policies and practices relevant to the national context. An initiative to introduce this intervention into existing maternal and child health (MCH) services in northeast Thailand was presented at the workshop. This initiative proposes to determine feasible and sustainable systems for delivering prenatal HIV counseling and testing, with provision of zidovudine and breast milk substitutes to seropositive women. The lessons learned from this ongoing project highlight the need for:

- An adequate and functional antenatal care system.
- Strong leadership within and close collaboration between the different programs involved.
- Capacity building for the provision of HIV counseling and testing services (including training of existing and incoming staff in HIV counseling specific to the MCH setting and establishment of HIV testing services with adequate referral systems from lower levels of service).
- Mobilization of resources for a reliable zidovudine supply (at the approximate cost of \$50 per mother-infant pair served) and the provision of breast milk substitutes for those in need.

The need to coordinate the different service providers involved while simultaneously preserving the

er's privacy and confidentiality poses a special  
nge. This requires creative use of staff time and  
nt organization.

ie participants from the region agreed that the  
ts of this intervention in Thailand are substantial  
at the experience in taking it to scale is  
raging. However, a number of participants  
sed reservations about its applicability to their  
ountries. Of greatest concern were human rights  
posed by the difficulties of maintaining informed  
it procedures and respecting the privacy and  
entiality of pregnant women. Experience in other  
of the world suggests that the acceptability of HIV  
during pregnancy is limited. Even in the optimal  
on of a clinical trial, in which the uptake of  
ary HIV testing is high, many women do not  
for their test results. The reasons for this are  
, but are probably at least in part related to fear  
found to be seropositive, they would be blamed  
child and/or the partner's infection and be  
d to stigmatization within the family, community,  
ital.

iers raised doubts about the lack of preparedness  
health system in their region. Maternity services

are already overloaded and would require considerable  
strengthening to cope with the increased workload that  
interventions to reduce MTCT require. Finally, resource  
implications in settings where HIV prevalence is low  
were discussed. In these settings, many women would  
have to be counseled and tested, at substantial cost, to  
identify only a few who are positive. This problem  
would persist even with a simpler and cheaper regimen,  
if it still required knowledge of serostatus.

Participants issued a call for further research to assess  
the feasibility, acceptability, and cost of different  
approaches to reduce MTCT in various settings in the  
region. At the same time, it was felt that more attention  
was required to meet the broader human and societal  
needs of the mothers themselves, especially with regard  
to confidentiality, stigmatization, and ongoing personal  
care and support. In an analogy to the critique of  
maternal and child health programs in the 1980s, the  
participants asked, "Where is the M in MTCT  
interventions?" There is an urgent need to articulate a  
set of comprehensive care and support services tailored  
to the needs of pregnant and postpartum women living  
with HIV as an essential complement to interventions to  
prevent MTCT.

## Service delivery models

In planning HIV counseling and testing programs, the challenge lies in improving access to services while ensuring that they meet basic standards with respect to the practice of informed consent, the quality of the counseling, the validity of the HIV test, and confidentiality. The participants reviewed various approaches to the organization of services, some of which have been successfully applied in the region.

Approaches to counseling were discussed first, as it was agreed that counseling forms the core of the intervention and indeed may be provided in the absence of HIV testing. Counseling may be conducted with individuals or couples, or in groups. The appropriate approach depends on the purpose and context of the intervention. For example, if the aim of counseling is to facilitate personalized behavior change, then individual-level, confidential counseling might be required, even though it is more time-consuming and resource-intensive. If, however, the setting is one in which group or family decision-making is important and shared confidentiality is valued, group counseling might be preferred.

Unfortunately, little is known about the processes and effects of counseling as it is practiced in many countries in the region. Participants voiced concern that counseling is often of poor quality, since most providers do not recognize counseling as an interactive process that requires a non-judgemental and trusting atmosphere. In addition, health education is often mistaken for counseling. The participants felt that more research is required to identify approaches that improve

the practice of counseling and to determine counseling modalities that best take into account local mechanisms for support and interpretations of privacy and confidentiality.

Basic structural models for delivering HIV counseling and testing services were discussed. These include public sector health facilities, NGO- or community-based services, private sector providers, or combinations of these that result from public sector/NGO partnerships and public sector/private sector partnerships. Each of these models presents advantages and disadvantages with respect to cost; quality assurance; acceptability; and ability to reach large numbers of clients or particular target groups. For example, voluntary counseling and testing services within public sector health facilities have the potential to reach large numbers of clients, but remain poorly utilized. The services provided are frequently undervalued by the community and may be of uneven quality because of pressures on staff time, the lack of incentives for staff, or limited resources. On the other hand, a private provider may provide excellent service but only to a small, selected group of clients. It may also be difficult to ensure that private sector facilities providing HIV testing and associated services meet minimum standards. NGOs have the potential to provide quality services but cannot usually be expanded or replicated as readily as public sector services.

One innovative model demonstrates how an NGO with expertise in voluntary counseling and testing

alizes on the NGO's customary strong rapport with community and the public sector's ability to reach a number of people. A consortium of NGOs has implemented such an initiative in a major public hospital in New Delhi, and provides voluntary HIV counseling and testing, including bedside counseling and follow-up counseling and support to affected individuals and families. This collaborative effort has had an impact on policies and practices throughout the hospital regarding appropriate use of HIV testing, the protection of the confidentiality of HIV test results, and the right of access to medical services. It has also facilitated a continuum of care through the establishment of linkages between other NGOs, community-based organizations, and health service providers in the community. The challenge for the combination model is managing the relationship between diverse partners from the public and the private health sectors.

Other service delivery models were proposed, such as voluntary HIV counseling and testing services provided by a network of NGOs and community-owned services targeting marginalized groups such as drug users and sex workers. These models emphasize the importance of strengthening linkages between different types of services and establishing effective referral procedures.

Discussion ensued about whether HIV counseling and testing should be provided free of charge or whether

some cost recovery would be possible. Some NGOs represented at the workshop charge a small fee for their HIV counseling and testing services, while the public sector usually provides these services free of charge. However, there was a sense that many clients would be willing to pay for these services, and in some countries a move exists to introduce a charge for HIV tests. A number of participants expressed concern that willingness to pay does not necessarily reflect ability to pay and argued that the government should continue to provide HIV counseling and testing services free of charge to low-income clients.

While there has been limited formal evaluation of most program efforts, the workshop participants concluded that the most promising service delivery models were those that address a diverse set of individual and community needs, including the establishment of strong linkages between HIV testing and PLWHA support services, the guarantee of adequate supplies of high-quality condoms, and efforts to sensitize all health service providers to the rights and needs of PLWHA. A strong recommendation was made to support operational research aimed at innovation, experimentation, and evaluation of a variety of service delivery models, especially those that explicitly bridge the gap between prevention and care programs.



# Implications of new technologies

Diagnostic technology has evolved rapidly since the first HIV antibody tests became commercially available in 1985. A wide range of HIV tests is now available, including many simple and rapid tests that are still uncommon but increasingly seen in the region, particularly in the private sector. The participants discussed the advantages and disadvantages of these new HIV tests.

The most commonly used method for the diagnosis of HIV infection is ELISA. Over the last few years, ELISA tests have improved enormously. They have increased sensitivity and specificity, are able to detect HIV-1/HIV-2 and variants, and have shortened the interval between infection and first detection of antibodies. ELISA tests are primarily designed for batch testing, making them suitable for use in surveillance and blood safety services. However, efficient use of ELISA tests requires a minimum number of specimens per run, making the system less flexible. In addition, their use requires sophisticated equipment and is technically demanding.

A wide range of simple and rapid HIV tests can now be used in laboratories with limited facilities. Most of these tests are presented in a kit form that requires no reagent or equipment. The simplicity of these tests reduces the chance of error. They can also be carried out by persons with no formal laboratory training. Simple/rapid tests are packaged either as single tests or in a format suitable for small batches of specimens, which allows for flexibility in the number of tests to be

performed at a time. Some also do not require refrigeration. Their use in low-resource settings has been shown to be more reliable, resulting in a better overall performance in the field than the ELISA tests. Although the cost per individual simple/rapid test may be higher, savings can still be possible in situations where small numbers of tests are carried out at one time.

The use of non-invasive HIV tests using saliva or urine samples was also discussed. They allow for the collection of samples at home, which can then be tested in a laboratory. Home testing is also becoming a possibility with some simple tests. While home testing is convenient, offers privacy, and appeals to such clients as repeat testers or health workers, concerns exist regarding quality assurance and the lack of support or follow-up for persons who test positive.

The participants recognized that simple/rapid testing would facilitate the expansion of voluntary counseling and testing services in resource-constrained settings where skilled laboratory technicians and laboratory services are scarce. Their use would also reduce the delay between testing and receiving the results, making it possible for clients to receive pre- and post-test counseling in a single visit. This in turn would reduce the proportion of people counseled and tested who do not return for their results, which is considerable in some settings. In antenatal care settings, a rapid diagnosis would reduce the delay in starting antiretroviral therapy and other interventions to reduce MTCT.

A number of participants, however, raised concerns about the introduction of simple/rapid tests into their settings, where there is inadequate attention to informed consent and confidentiality. They felt that clients who attend pre-test counseling should have adequate time to reflect upon their decision to be tested and have the opportunity to seek support from others before arriving for post-test counseling. The use of simple/rapid tests may also increase the risk that HIV tests would be used in a coercive way, in clinical and non-clinical settings. Chilling accounts were given of health providers, the police, or even insurgency groups

insisting on knowing the HIV status of persons under their protection. The availability of home-based tests raises fears that some individuals, particularly women, might be forced to undergo an HIV test by their sexual partners. Finally, some participants felt that quality control was still a significant issue with simple/rapid tests, not the least because a confirmatory test is still required in the case of an initial positive result and because the referral system is inadequate. These participants urged that access to simple/rapid tests be tightly controlled and that extreme caution be exercised in their use.

# Ethical and legal issues

An in-depth discussion was then held to review ethical and legal issues that arise in the practice of HIV counseling and testing in the region. These tend to revolve around informed consent and confidentiality, which are often neglected by the public, policy-makers, and health providers.

Counselors and health providers who are concerned about ethical and legal issues face many complex dilemmas in their clinical practice. They may feel that their first responsibility is to their client, but in many cases they are expected to comply with requests for HIV testing coming from other persons, such as family members, employers, and the police. Premarital HIV testing was given as an example. While this is desirable in principle, it raises many difficulties in settings such as India and Nepal, where arranged marriages are the norm. Families or marriage brokers have been known to demand HIV tests without the proper consent of the persons who are to get married (who generally have very little influence over the whole process anyway), and then disclose positive results. This practice is becoming more and more common, leading to traumatic situations. There are fears that premarital testing conducted in this way will deter persons at risk of HIV infection from being tested and increase the likelihood of falsified certifications prepared by unscrupulous brokers and providers. Counselors and health providers also encounter many stressful situations in counseling and supporting positive clients who are reluctant to disclose their HIV status to their sexual partners through fear of consequences for themselves, their children, or their

families.

The legal principles that underpin informed consent and confidentiality were reviewed, with a particular focus on the situation in India, where these have been the subject of extensive public debate. The right of competent adults to make decisions about their bodies and health care and to refuse undesired medical procedures is protected in common law. The general rule is that consent for significant medical procedures must be obtained. The participants felt that distinction should be made between HIV and other common diagnostic tests, in view of the potential harmful consequences of a positive result, including stigmatization, discrimination, domestic violence and stress because of the fatal course of HIV infection. Consent to another diagnostic test cannot therefore be taken as implied consent to an HIV test. An HIV test must be preceded by informed consent and accompanied by pre-test and post-test counseling, which are now generally accepted as the standard of care in HIV testing. There is concern that this rule is generally not respected, in part because of the unequal relationship between medical professionals and their patients.

The duty of health providers to maintain confidentiality of medical information also emerges from common law principles. In India at least, the law and medical ethics recognize that supporting the duty of health providers to protect the confidentiality of information shared with them by their patients is in the public interest. However, disclosure is permissible in certain circumstances when a stronger public

lose outweighs the public interest to maintain confidentiality. The duty to warn or protect third parties is generally considered to be secondary, and comes into play only when another recourse has been attempted. Thus, a health worker who is providing care to an HIV-positive client and is concerned about other persons who may be endangered should first urge clients to voluntarily notify contacts and to take action to minimize the risk of further transmission. Only if this is ineffective, should a health worker consider taking further steps to warn or protect third parties.

A discussion ensued about a recent case before the Supreme Court of India. In this case, the court upheld the legality of the disclosure of an individual's positive status by a medical institution to which he had donated blood, and "suspended" the rights of PLWHA to marry. The participants expressed considerable concern about the negative repercussions of this precedent. Until now, the policy has been to bestow responsibility for prevention of HIV on individuals. By placing PLWHA of this responsibility and casting the blame on health professionals, there is a danger that the principles of confidentiality and protection of individual rights will be jeopardized, and affected individuals will be driven underground.

In other countries in the region do not have laws restricting the identification of PLWHA by health workers or curtailing the rights of PLWHA to marry. In Thailand, the prevailing policy respects the autonomy of individuals and upholds the basic principles of

informed consent and confidentiality. In practice, HIV-positive people are counseled to protect their partners; the decision to disclose, however, usually remains with infected individuals.

Nevertheless, participants recognized that existing legal provisions in their countries are inadequate or insufficient to address difficult issues, such as how to balance confidentiality against the protection of third parties at risk. Many problems are encountered in settings where the practice of common law is discretionary and uncertain, ethical standards in medical settings are low, understanding about the HIV epidemic is poor, and levels of fear, stigmatization, and discrimination are high. In such settings the common law that typically protects individuals from violations of confidentiality in health care settings may be ignored by providers and institutions seeking to address a public interest that they personally perceive to be more valuable. Such decisions are often made by individuals with limited understanding of the facts concerning HIV infection, its transmission, and the social consequences of disclosure.

There is therefore an urgent need to establish robust statutory legal frameworks for HIV testing, informed by public health expertise and human rights concerns. Promulgation of such laws should be preceded by extensive consultation (especially with PLWHA organizations) and a review of legal protection mechanisms established in countries that seek to protect the rights of PLWHA.

## Conclusions and recommendations

The workshop participants represented several countries in the region, and came from a tremendous diversity of settings. Yet it became apparent that they faced many common problems in their involvement in HIV counseling and testing services, largely because the purposes of such services are widely misunderstood and they are often misused to track down and isolate infected persons.

The participants made a strong plea for strengthening the counseling component of HIV counseling and testing programs, in order to move from "VCT" to "VCt" and to integrate HIV testing services into more comprehensive programs of HIV prevention and care. This is critical for PLWHA, for whom HIV counseling and testing should serve as an entry point to a continuum of care program. A number of approaches to the planning and organization of voluntary HIV counseling and testing services were reviewed. There was consensus that promising service delivery models merit further exploration, with a view to expanding access while maintaining basic standards and quality assurance.

Participants discussed the pivotal role of voluntary HIV counseling and testing services in interventions to prevent MTCT. They urged that more attention be paid to protecting mothers' rights to consent, confidentiality and ongoing personal care and support. Many participants expressed reservations about the readiness of

the health system in their own settings to take on these important but demanding interventions.

Considerable concern was expressed about the ethical and legal dimensions of HIV counseling and testing in the region. There was consensus that widespread stigmatization and discrimination against PLWHA and insufficient attention to basic ethical principles such as informed consent and confidentiality deter people from seeking HIV testing, discourage voluntary disclosure, interfere with behavior change, and thus contribute to the continued transmission of the virus. The participants emphasized the need for more purposive action to protect the human rights of infected and affected persons. This requires public debate on and advocacy for the rights of PLWHA, as well as the development of policies and laws to provide guidance in difficult situations and to prevent harmful practices such as mandatory HIV testing.

Finally, the participants recommended that further operations research be conducted to address uncertainties about the role of HIV counseling and testing programs in the diverse settings of the region. They identified a number of questions for operations research required in support of the development and expansion of these programs, as described in the next section.

# Operations research questions

## Developing HIV counseling and testing programs

What are the minimum requirements, with respect to HIV prevention services, care and support services, and a supportive community environment for individuals who test positive, that should be in place before stimulating a demand for voluntary HIV counseling and testing?

What are effective strategies for mobilizing and sensitizing communities in order to increase acceptance of voluntary HIV counseling and testing programs and to reduce discrimination and stigmatization against PLWHA?

To whom should HIV counseling and testing services be extended as a priority? How is this best achieved?

What is the appropriate mix of counseling services and HIV testing services?

## Delivering services

What are appropriate models for organizing and delivering HIV counseling and testing services in different settings, in order to improve access and increase coverage while maintaining quality services?

What are suitable strategies to protect privacy, informed consent, and confidentiality in integrated service environments requiring referrals among different services and sectors?

- Under what circumstances is it safe, appropriate, and cost-effective to introduce new HIV testing technologies, including simple/rapid tests and home-based tests in a given health care setting?
- How can PLWHA be more effectively engaged in the planning and implementation of HIV counseling and testing services?
- What are effective models for support groups for affected persons?

## Ensuring quality of services

- What are effective strategies for sensitizing health providers about the needs and rights of PLWHA and for training and supporting them to conduct appropriate HIV counseling and testing when required? What interventions are required to discourage harmful practices such as mandatory HIV testing, ensure pre-and post-test counseling, and promote confidentiality in health care settings?
- How can the content and practice of HIV counseling be improved, taking into account client expectations, local interpretations of privacy and confidentiality, available resources, and mechanisms for care and support to PLWHA? What are the most suitable approaches for training and supporting health providers in counseling?
- What are the minimum standards for HIV testing (in terms of the informed consent process, the quality of pre-and post-test counseling, the validity and reliability of the HIV test, and the result round

turnaround time)? What are appropriate systems to ensure quality assurance in different settings?

- How can HIV counseling and testing best be used to effect and sustain behavior change for HIV prevention, both for clients who test negative and for those who test positive?
- Are there ways to reduce the resources involved in counseling clients who test negative, without compromising quality or confidentiality?
- How can counseling best address the needs of clients who test positive (in situations of post-test counseling, ongoing counseling, interventions to reduce MTCT, referrals for care and support services, home-based care, etc.)?

## **Developing interventions to reduce MTCT**

- What are the feasibility, acceptability, and cost-effectiveness of different approaches to offering HIV counseling and testing to pregnant women in programs to reduce MTCT?

- What are critical considerations in deciding whether HIV screening should be offered to all pregnant women seeking care from a particular MCH facility (HIV prevalence in the client population, uptake and timing of maternity services, availability and quality of counseling services, availability of interventions to reduce MTCT, access to care and support for infected women)?
- What are appropriate models for delivering HIV counseling and testing services in MCH services, with special attention to the need to maintain confidentiality and sustain the quality of other critical services in an integrated service environment?
- When is it appropriate to involve partners in HIV counseling and testing provided in the context of MCH services, and how is this best achieved?
- What is the impact of HIV counseling and testing and other interventions to reduce the risk of MTCT on the quality of life of mothers who test positive, and how can negative effects be mitigated?

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# Workshop agenda

**Monday, 1 February 1999**

## Introduction

09.00-09.30 Objectives and organization of the workshop (de Zoysa)

Keynote address (Salunke)

Introductions

09.30-10.00 Overview of issues (van Praag)

Discussion

10.00-10.30 Break

## Contribution of VCT to HIV prevention

Chairperson (Guest)

10.30-11.00 Results of AIDSCAP/WHO Voluntary HIV Counseling and Testing Efficacy Study (Kamenga)

Discussant's intervention (Gangakhedkar)

Questions and comments

11.30-12.30 Panel discussion

Participants (Bharucha, Sokhey, Mutarakosa, George)

12.30-13.00 General discussion

13.00-14.30 Lunch

## Role of VCT in the prevention of MTCT

Chairperson (Hira)

14.30-14.50 Presentation and discussion of Thai vertical transmission intervention trial results (Teeraratkul)

4.50-15.10 Presentation of follow-up programmatic activities (Kanshana)

5.10-15.30 Discussion

5.30-16.00 Round table:

Comments on implications of trial results for VCT in the context of ante-natal clinics (Sutwantha, Gurubacharya, San, Hong, Sarkar)

00-16.15 Break

15-18.00 Small group work

**Tuesday, 2 February 1999**

## Role of VCT programs in care and support for PLWHA

Chairperson (Sundararaman)

09.00-09.15 Introduction (Ungphakorn)

09.15-10.00 Panel discussion:

Participants (Nadkarni, Suwannawong, Sharma, Gordon, Rau)

10.00-10.45 Discussion

10.45-11.00 Break

## Service delivery models

Chairperson (Salunke)

11.00-11.15 Overview of issues (MacNeil)

11.15-12.15 Possible implications of new technologies (MacNeil)

12.15-13.00 Discussion

13.00-14.30 Lunch

14.30-17.00 Small group work

17.00-18.00 Film ("Hidden Lives")

**Wednesday, 3 February 1999**

## Ethical and legal issues

Chairperson (Elias)

09.00-09.15 Overview (Dhaliwal)

09.15-10.30 Round table

Informed consent, confidentiality, and the judgement of the Supreme Court of India (Salunke, Solomon, Grover, Pandian, Ungphakorn)

10.30-11.00 Discussion

11.00-11.30 Break

11.30-13.00 Small group work

13.00-14.00 Lunch

14.00-15.30 Reports of working groups and discussion

15.30-16.00 Summary, action points, wrap-up and close